

# SURVIVORSHIP AND BREAST CANCER IN YOUNG WOMEN

The ACBCYW Subgroup on Survivorship

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- ▶ **Recommendation:** ACBCYW should *embrace* the NCCS definition of a survivor
  - ▶ Survivorship after cancer starts at the point of diagnosis and extends to the end of life and embraces anyone touched by the experience, including caregivers
    - ▶ Offers a more holistic view of survivor
    - ▶ Acknowledges that some may choose not to (or to) define themselves as such
- ▶ **Recommendation:** Any woman **diagnosed** with breast cancer before age 45.
  - ▶ **Recognize** that some issues may occur/continue past this age

## DEFINING A YOUNG BREAST CANCER SURVIVOR

- ▶ Sexuality and Body Image
- ▶ Fertility
- ▶ Spirituality
- ▶ Mental Health
- ▶ Healthy Lifestyles
- ▶ Financial burden

## WHAT ARE THE ISSUES?

- ▶ Sexual dysfunction is prevalent
  - ▶ Estimates vary: 30-100%
- ▶ Our understanding is limited
  - ▶ Issues in women without partners, women who have sex with women, women with MBC are not well characterized
- ▶ Lance Armstrong Survey, 2010:
  - ▶ Sexual dysfunction is tied to other issues including depression, negative body image, and couple discord
- ▶ **Recommendation:** Raise awareness of sexual side effects for both patients and providers by coordinating access to education with partners

## SEXUALITY AND BODY IMAGE

- ▶ Fertility concerns are of paramount importance
- ▶ ASCO Guidelines on fertility preservation are in place, but access to information remains a challenge
- ▶ Fertility concerns are tied with financial concerns
- ▶ **Recommendation:** Increase awareness of fertility needs and issues, stressing importance of early access. In addition, ACBCYW could **advocate** for insurance coverage of fertility preservation.

# FERTILITY

- ▶ Search for meaning and purpose, and the experience of the transcendent
- ▶ Includes religion but is *not* synonymous with it
- ▶ Spirituality is a critical aspect of survivorship care
  - ▶ Characterization in young women is limited, but the sense that one is alone after breast cancer, may be a pronounced issue.
- ▶ **Recommendation:** Survivorship care planning should integrate spirituality

## SPIRITUALITY

- ▶ Cancer at a young age is a known risk factor for poorer mental health (compared to dx at an older age)
- ▶ Alterations in mental health include:
  - ▶ Heightened anxiety and distress
  - ▶ Genitourinary symptoms of menopause due to chemotherapy
  - ▶ Treatment-related cognitive dysfunction and neuropathy
  - ▶ Disruption of life goals
- ▶ **Recommendation:** Raise awareness of the mental health toxicity associated with breast cancer and treatment. Highlight importance of treatment.

# MENTAL HEALTH

- ▶ Risky health behaviors contribute to worse outcomes, including poorer quality of life and potentially, higher relapse or secondary cancer rates.
- ▶ Recent data suggest smoking among young women with breast cancer remains common
- ▶ **Recommendation:** Collaborate with ongoing efforts focused on reducing risky behaviors, including smoking cessation, messaging about healthy lifestyles, and reducing obesity

## HEALTHY LIFESTYLES



- ▶ Think beyond the impact in terms of “dollars and cents”.
- ▶ Include the “Opportunity Costs” faced by young women with breast cancer
  - ▶ Life goals may be delayed or deferred (eg, college)
  - ▶ Work/career may take a backseat
- ▶ Treatment has a direct impact on financial burden
  - ▶ Variability based on insurance coverage and individual plans
- ▶ **Recommendation:** Identify resources for women struggling with financial needs so they can access them more easily.

## FINANCIAL BURDEN

1. Expand surveillance activities so we can capture patient reported outcomes. This can be done through collaboration with ACBCYW partners.
2. Emphasize known resources across the country to meet survivorship needs.

## FINAL RECOMMENDATIONS